From epistemic violence to dialogue in mental health care research:

Reflections on a collaborative research process

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I am not the object of research because I am not an object of any kind, I am a full human subject. The stigma of mental illness is that it is a sign of a deficit in the person marked, that we are not complete subjects, a deficit which has a profound impact on our ability to reason for ourselves, distinguish reality, get anything in perspective, in short, to achieve any kind of maturity as a person.

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Introduction

Within the recovery discourse in international mental health care policy, practice and research, the personal perspectives and experiences of persons with mental health problems are taken to be of great importance (Velpry, 2008). Policy makers and professionals increasingly see persons with mental health problems as experts of their own recovery process (Davidson et al., 2005; Slade & Hayward, 2007; Stanhope & Solomon, 2007). Consequently, rather than focusing on professionally-defined therapeutic goals, recovery-oriented support should be tailored to the personal perspectives, experiences and preferences of its service users (Slade & Hayward, 2007). As experiential knowledge becomes all the more necessary to understand what it means to be in recovery and how support should be organized, academic research on mental health increasingly focuses on the lived experiences of persons with mental health problems. These findings are collected in a still-growing evidence base that can be placed on a continuum ranging from research that merely collects service users' voices (e.g., through ethnographic and phenomenological methods) to research that is fully controlled by service users themselves (Beresford, 2005; Pilgrim, 2009; Stanhope & Solomon, 2007).

In sharp contrast to this consensus on the importance of experiential knowledge, several authors within the user/survivor movement have raised questions about how the personal experiences and perspectives of persons with mental health problems are still overshadowed, and even marginalized, by professional and academic voices in today's recovery era (Beresford, 2005; Costa et al., 2012; Crepaz-Keay, 2016; Faulkner, 2017; Grey, 2016; Jones & Brown, 2013; Russo, 2016; Swerdfager, 2016; Voronka, 2016). In this respect, Liegghio (2013) refers to the concept of epistemic violence, originally used in post-colonial studies to describe how institutional practices disqualify certain groups in society as legitimate knowers. In psychiatry, epistemic violence occurs when the personal experiences and perspectives of persons with mental health problems are reinterpreted and reduced to professional explanations and labels that represent the person (e.g., through the use of the DSM) (Liegghio, 2013; Pattadath, 2016). As a result, persons with mental health problems are "rendered out of existence by the assertion that their experiences are 'disordered,' or the symptoms of a 'mental illness'" and become invisible within society (Liegghio, 2013, p. 125). Several authors highlight how this epistemic violence is also maintained and reproduced in academic research, in various ways (Russo, 2016). For example, some authors warn for the risk of homogenizing experiential knowledge, referring to the whitewashing of any diversity in the way people with mental health problems make sense of their experiences and reducing them to their common 'psychiatric' identity, disregarding other aspects of their identities and the individuality of their experiences (Rose, 2017; Russo, 2016; Voronka, 2016). Moreover, such a homogenized representation of lived experience risks being used by policy makers and academics in a sanitized and strategic way, which fits comfortably into their own dominant paradigms (Costa et al., 2012; Leblanc & Kinsella, 2016). This is also described by Grey (2016) as 'benevolent othering', a process that "involves simplistic and self-serving representations that gloss over the complexity and diversity of people's lives, constructing a self-affirming image of 'benevolent subjects' as superior and masterful" (Grey, 2016, p. 243). Another related question that comes to the fore is one of narrative ownership: who does the story belong to (Russo, 2016)? To what extent has the research agenda been co-produced (Grey, 2016)? Participants share their personal experiences with researchers, but as they are often not involved in the further stages after data collection, their own perspectives unavoidably become compromised by the researcher's interpretive gaze (Costa et al., 2012; Russo, 2016; Smythe & Murray, 2000).

These findings illustrate how the discursive dominance of mental health professionals and policy makers is reproduced through the power inequalities that remain inherent to researcher-subject relationships in academic research (Swerdfager, 2016). As a result, the voices of persons with mental health problems are once again silenced by dominant paradigms of illness and recovery (Faulkner, 2017). Even when focusing on lived experience, academic research into mental health still tends to produce a scientific monologue in which the researcher has the last word about the subject's experiences. Therefore, alternative research approaches and different, more equal ways of relating are much needed (Beresford & Menzies, 2014; Russo, 2016; Russo & Beresford, 2015). To disrupt processes of epistemic violence, several user/survivor researchers stress the importance of a shift towards survivor-controlled research and 'truly' co-productive research between academics and persons with lived experience in which a co-produced agenda aims to challenge dominant ideas and entrenched assumptions (Beresford, 2005; Faulkner, 2017; Pilgrim, 2009).

Until now, however, few concrete research accounts have described *how* such co-production comes about, what possible form it can take, and *how* the researcher-participant relationship can be rethought to a more equal partnership. The aim of this article is to share our experiences and reflections on a co-productive research project that we, Clara (an academic researcher) and Pete (an expert by experience), conducted between May 2016 and January 2018 (De Ruysscher, Tomlinson, Vanheule, & Vandevelde, 2018). Our collaborative case study started from a bricolage approach and focused on Pete's experiences regarding recovery and psychiatry. In this article, we will reflect on how this research project was carried out, which methodological choices were made and how these choices shaped our research relationship.

Unraveling our research process

We first met at Villa Voortman in January 2013, a community-based meeting place in Ghent (Belgium) that aims to offer a welcoming shelter for persons with co-occurring psychosis and addiction problems (De Ruysscher, Vanheule, & Vandevelde, 2017). In Villa Voortman, visitors (as service users are called) are free to organize and take part in a wide range of activities and workshops (e.g., poetry, music, cooking, sports, philosophy). At that time, Pete was an enthusiastic and committed visitor of the meeting place, organizing writing and philosophy workshops for other visitors. Clara spent time there in the role of intern, as part of her education to obtain a MA degree in Special Needs Education. Although Pete did not suffer from psychosis at that time, he had already spent almost two years in mental hospitals, where he had been treated for depression and addiction. However, from July 2013, Pete developed his first full-blown psychosis, which caused a series of further (involuntary) admissions, major disruptions in his social life and the loss of contact with his teenage daughter. In September 2015, Pete recovered from this psychosis and started visiting Villa Voortman again which is where Clara and Pete picked up. In 2016, by that time working as a researcher in the field of Special Needs Education, Clara conducted a qualitative study in Villa Voortman in order to gain insight into how an alternative approach for persons with co-morbid psychosis and addiction problems can take shape (De Ruysscher, Vanheule, et al., 2017). As one of the visitors, she also interviewed Pete about his experiences in the meeting place.

In the wake of that study, the mutual communication intensified, leading to a continuous exchange of thoughts and ideas regarding psychiatry and recovery. Initially, we talked a lot about Pete's time in mental hospitals during his psychosis. Also, Pete let Clara read the texts and poetry he had been writing on his experiences regarding psychosis, psychiatry and recovery. Gradually, Clara also started sharing with him her doubts and worries about the centrality of the recovery framework in her own research ("To what extent is the recovery framework meaningful to the participants of my studies? Am I doing justice to their stories by focusing on recovery, rather than, for example, social inequality?") (Naert, De

Ruysscher, & Schiltz, 2018). This interaction led to the joint decision to turn this exchange of thoughts into a research project of its own and to start recording our conversations.

Although there was no clearly defined research agenda or purpose at that time, a total of nine conversations were recorded and transcribed between May 2016 and January 2018, all primarily focusing on Pete's personal experiences with recovery and psychiatry. Besides a few exploratory questions at the start (How did you experience your admissions and treatment? What do you think of recovery?) no predefined interview guide was used, as each conversation prompted new themes to be discussed in the next conversation. In doing so, data collection and analysis continuously alternated; each conversation was analyzed and discussed in preparation for the next conversation, until no further questions and themes came up. Looking back on those conversations, the topics discussed were the aspects of psychiatry that most bothered Pete at that time: problems with drugs, continuity of care, identity issues and rebuilding your life after an illness. By focusing on Pete's experiences of recovery, both in the sense of his experience of recovering from psychosis and his ideas on today's recovery era in mental health care, it became clear how they are in tension with more professional enactments of recovery as mental health care policy and practice (McWade, 2016). For example, although recovery is conceptualized as a non-linear and unique journey towards living a meaningful life, Pete experienced that he was often urged by psychiatric staff to lower his aspirations for his future (e.g., having a job, having a social network outside psychiatry). These low expectations of staff show how a medical approach of mental illness is still present in mental health care, characterized by thinking in terms of deficits rather than strengths and the assumption that mental illness is chronic. Moreover, the challenges that Pete faced during his recovery process were all of a social nature, such as fighting stigma, coping with social isolation and rebuilding his family life. However, during his admissions, these vulnerabilities were often not perceived as of a social nature but as intrapersonal. Also, Pete experienced that he was reduced to a 'person with an illness' and that other aspects of his identity (being a father, poet, citizen) became invisible. In that sense, Pete's experiences illustrate how individualized conceptualizations of recovery (e.g., the CHIME framework) fall short in addressing the

social and interactional nature of both mental illness and recovery (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011). In other words, today's recovery ethos simultaneously appears as a hopeful vision of empowerment and an expert-driven discourse that fails to address the social realities of people in recovery and in which diagnoses still have a major impact.

Discussing these tension points resulted in a critical paper about the professionalization and operationalization of the recovery concept (De Ruysscher, Tomlinson, Vanheule, & Vandevelde, 2018). As with the data collection and analysis phase, the writing process was also completed in a co-creative way. This is well illustrated by the way we dealt with the conversation data. The original conversations took place in Dutch and were transcribed by Clara. However, based on the agreed themes, extracts were selected and translated into English by Pete (a native English speaker). This gave Pete the chance to revisit his ideas in detail, rephrase what he had said and add nuances. In addition, Clara gained insight into Pete's experiences by reading his poetry and through email conversations during the research process. This way of working is in contrast to a more traditional interviewing process in which the participant is often not given much space to reflect upon the questions, since all processing and interpretation of ideas is done by the researcher alone. Clara also provided relevant academic papers on recovery that were read together, which gave Pete more confidence in using the philosophical vocabulary that he had developed passively over many years of reading but had never used in his writing.

"I'll play it first and tell you what it is later": bricolage

In line with Miles Davis' famous jazz premise, it was only after we started recording our conversations that we sought inspiration from methodological concepts that could help describe the journey we were traveling. In doing so, we found several points of recognition in the field of critical pedagogy, more precisely in the concept of *bricolage*. The concept first appeared in *The Savage Mind* of anthropologist Lévi-Strauss (1968), who uses bricolage as a metaphor to advocate a multi-faceted approach to

meaning-making in which fieldworkers assemble and combine all possible tools available (e.g., observations, hypotheses, social practices, dominant discourses, narrative techniques) to produce relevant knowledge (Earl, 2013; Lévi-Strauss, 1968; Rogers, 2012). At a later stage, the concept of bricolage was adopted by Denzin and Lincoln (2011) who define bricolage as a multi-methodological research approach that adds rigor to social inquiry, because it respects the complexities and contradictions of the social world (Denzin & Lincoln, 2011). Building on Denzin and Lincoln's work, Kincheloe describes critical bricolage as a continuous hermeneutic search for more layered and rigorous ontological insights, starting from the assumption that "any social, cultural, psychological or pedagogical object of inquiry is inseparable from its context, the language used to describe it, its historical situatedness in a larger ongoing process, and the socially and culturally constructed interpretations of its meaning(s) as an entity in the world" (Kincheloe, 2001, p. 682). Rooted in an "epistemology of complexity" (Kincheloe, McLaren, & Steinberg, 2011, p. 168), researchers-asbricoleurs thus recognize that knowledge is always temporary, questionable, ever-changing, specific to the cultural context and subject to power dynamics at play (Kincheloe, 2001). In search of richer and more complex forms of knowledge, bricoleurs apply an active attitude towards research methodology. Rather than predetermining and passively following standard research methods and procedures, they allow the context to prompt relevant questions and creatively combine empirical methods in a quest for understanding (Van Hove, De Schauwer, & Platel, 2017). In this process, a central place is given to forms of knowledge 'from the margins' which do not fit established research formats, and thus often remain unheard or are considered invalid. In this way, they challenge the dominant researcher-asneutral-observer versus research subject-as-passive-object dichotomy and consider the research process itself a political act, aiming to disrupt such power relations (Rogers, 2012).

Whilst the concept of bricolage offered us some theoretical and practical guidance during and after our research process, we also made our own interpretations of some of its core ideas. The methodological flexibility that is an important feature of bricolage is also characteristic of our research process, in which there was no predetermined research plan to determine the course of our journey

and no interview guide to structure our conversations. Instead, each step of the process was allowed a dynamic of its own and shaped the next step. This flexible, step-by-step approach generated a creative dynamic between us, in which we freely reflected out loud, generated and discussed hypotheses and shared our thoughts and doubts about the subject matter. These dynamics added to the unpredictability and openness of the research process but at the same time meant that we gradually developed a common language with which to talk about Pete's experiences of recovery and mental health care. This common language made it possible for us as co-writers to continuously learn from each other, refine our own viewpoints and enrich each other's writing. Importantly, this common language neither represents the researcher as the knowing observer nor the untouched lived experiences of the research subject. Of course, our research relationship remained asymmetrical – the study focused on Pete's lived experiences, not Clara's - but was not characterized by an epistemological hierarchy. Instead, we would describe our relationship as one of colleagues in a multidisciplinary cooperation. As Clara is a qualified researcher in Special Needs Education, her staff/researcher perspective contrasts with Pete's experiences of mental health care as service user. Additionally, although we are both writers, we differ in age, gender, social class, academic schooling, native language and lifestyle. Rather than trying to neutralize or 'objectify' these different subjective perspectives, our research journey can be seen as a relational meaning-making process, as knowledge was constructed precisely in the interplay and tensions between our unique, at times divergent or even contradictory, voices and perspectives (Frølunde, 2013; Phillips, 2011).

Dialogue as ethical imperative

The aim of this paper is to share reflections and experiences on the co-creative research journey that we – Clara and Pete – have traveled together. In that process, aware of the power imbalances at play in mental health care practice and academia, we searched for a research approach that did not reproduce epistemic violence and allowed for more equal ways of relating to each other as researcher

and research subject. Along the way, we found theoretical and methodological inspiration in the concept of bricolage, which can be described as a continuous search for more rigorous forms of knowledge production, working to expose complex social realities and disrupt dominant social discourses by giving a central position to subjugated and marginalized voices (Rogers, 2012). Whereas Kincheloe (2005) argues that such rigor can be achieved through methodological flexibility and the use of critical hermeneutics (Kincheloe, 2005), we experienced the necessity of a radical and far-going collaboration between us in every step of the research and writing process. It was the ethical imperative to continuously keep an open-ended dialogue between us alive that provided our research process (and the knowledge we produced) with rigor. Based on this experience, we elaborated our own interpretation of the rejection of monological research in bricolage. Kincheloe (2005) rejects (positivist) research as monological when it ignores the complexity of lived reality and fails to address research subjects as things-in-the-world (rather than static things-in-themselves). However, we view research as monological when it fails to disrupt the epistemic hierarchy between the researcher and the research subject and thus reproduces mechanisms of epistemic violence. Applying a dialogical approach to mental health care research is not merely a methodological choice, but above all an ethical responsibility. Building on the work of Bakhtin (M. Bakhtin, 1984; M. M. Bakhtin, 1981), Frank highlights two core characteristics of dialogical research: creating space for the narratability of the research subject's experiences (Frank, 2002) and respecting the unfinalizability of the research process (Frank, 2005). In what follows, we will reflect on both characteristics in relation to our bricolage journey.

Talking about the dialogical ethics of narrative analysis, Frank (2002) argues that what constitutes a story lies in its *narratability*, i.e. the extent to which "events and lives are affirmed as being worth telling and thus worth living" (Frank, 2002, p. 111). Applied to our research process, the central importance of narratability is best illustrated by asking ourselves the following question: what benefits did Pete get from engaging in this collaborative research project? For Pete, researching his own situation made it possible to tell a clearer and more stable story of what happened to him, which was

experiences (both in and out of psychiatry) in which his personal perspectives were trivialized or reduced to a psychiatric label, leaving no room for Pete's actual story. He articulated this in the following way in an email to Clara: "Writing this article, together with other extensive writing in poetry and quasi-scientific prose has made my recovery possible, and literally on my own terms. My vision of myself and my situation does not begin with a formula urged on me by a psychiatrist." In other words, creating space for the narratability of Pete's perspective on his recovery and treatment did not only make his experiences visible, but also attributed a sense of reality to them. Looking back on our bricolage journey, several factors have contributed to a research dynamic in which this space was continuously (re)shaped and kept open: the methodological flexibility, the openness of our research agenda, and especially the fact that we developed a common language that allowed us both at any stage to exchange and revisit ideas, add nuance and return to our steps when necessary.

Related to the idea of *narratability*, Frank (2005) also refers to the importance of respecting the principle of *unfinalizability*, i.e. the avoidance of any monological interpretations or fixed descriptions of people's personal experiences and perspectives. Considering dialogue as a process with no predefined beginning or end, he highlights how "in a dialogical relation, any person takes responsibility for the other's becoming, as well as recognizing that the other's voice has entered one's own" (p. 967). In other words, in the dialogical process, the researcher and research subject find themselves in an equal and co-creative relationship that is characterized by interdependence, a continuous mutual influence and the recognition of each other's unique perspectives and vulnerabilities (Granek, 2013). Aware of the *unfinalizability* of Pete's experiences and our research process, we did not aim to give a finalized representation of 'who Pete is' nor to seek consensus between Clara's academic perspective and Pete's experiential voice. Although our research is the result of the dynamic that occurred when we came together in a shared space and time and influenced each other, it also cannot be understood as a mere reflection of a personal process between us. Whilst Pete's experiences all involve him, most of them also involve other people or interactions with (his ideas about) society as a whole. Likewise,

Clara's ideas on recovery and mental health care are shaped by several professional, personal and academic influences. Consequently, our encounters gave shape to an ever-changing field of arguments, infused by a multitude of perspectives and voices (Frank, 2005; Leong, Wright, Vetere, & Howard, 2010). Characteristic to this field is that the researcher and the research subject do not aim to finalize one another, which makes it hard or even impossible to reach a fixed synthesis; emerging tensions between different perspectives are not resolved but explored and made visible. Instead, in line with the idea that "the meaning of any present story depends on the stories it will generate" (Frank, 2005, p. 967), our collaborative research project should be considered a small part of an ongoing process and above all an invitation for readers to join in our dialogue. Drawing a monological portrait of Pete based on his experiences would have been unethical, for it would reduce him to a static description, denying him the right to outgrow or change his perspectives, thus reinforcing power inequalities and mechanisms of epistemic violence.

Looking back on our research process, it was only through discussing Pete's personal experiences so extensively and dialogically that we could expose tensions and gaps in today's mental health care (i.e. the professionalization of recovery) in such depth. Indeed, it has been argued that micro-level experiential knowledge holds the potential to address wider political and social developments and to challenge dominant discourses (Stanhope & Solomon, 2007; Swerdfager, 2016). However, connecting experiential knowledge to wider policy developments is only possible when the experiences of persons with mental health problems are *narratable*, both to themselves and others, and seen as *unfinalizable*. Assuming that their perspectives are crucial for understanding recovery and should form the foundation of recovery-oriented policy and practice (De Ruysscher, Vandevelde, Vanderplasschen, De Maeyer, & Vanheule, 2017; Stanhope & Solomon, 2007; Velpry, 2008), *narratability* and *unfinalizability* are indispensable principles, as they give dialogical research the potential to unsettle entrenched ideas about other people's realities (e.g., living with mental health problems) and to dismantle them from their static character (Frank, 2005).

Concluding reflections

co-creative or dialogical research. Rather, by unraveling our research process, we aimed to share reflections on the methodological openness of applying a bricolage approach and the ethical implications of developing a more equal research relationship. Keeping the heterogeneity of lived experience and the diversity of co-creative research trajectories in mind, we want to conclude this article by reflecting on a number of specific circumstances that had an impact on our research process. A first important factor is the place and context in which we met and had most of our conversations for this research project: Villa Voortman. An essential feature of this meeting place is that it works as horizontally as possible. In Villa Voortman, power inequalities (e.g., between staff, volunteers and service users) are minimized, in strong contrast to the strictly hierarchical structures of other psychiatric settings (De Ruysscher, Vanheule, et al., 2017; Vandevelde et al., 2015). Villa Voortman as a place that facilitates equal encounters has undoubtedly helped shape the dialogical way in which our research relationship (and friendship) was built. In addition, a number of personal factors have shaped our collaboration. Besides the fact that Pete has the lived experience of dealing with psychosis and being a service-user of mental health care facilities, he also considers himself in an advanced stage of his recovery process and has followed a training course to become a qualified peer worker. Clara is in the final stage of her PhD which focuses on recovery of persons with complex mental health needs, her thinking on recovery has developed and progressed under influence of previous research projects, encounters with other (ex-)service users and academics, and critical literature (e.g., Mad Studies). However diverse our backgrounds and experiences may be, they did lead us to a shared strong interest in conceptualizations of recovery and the organization of Flemish mental health care. Also, Pete's competences of being a native English speaker and an active writer (prose and poetry) fit well within the academic standard of writing scientific papers.

It was not our intention to present our collaborative journey as a 'best' methodology for conducting

Whilst these specific factors brought us together and defined the shape of our research relationship and process, they also made us aware of the singularity of our collaboration. If we want to move from monological research that reproduces epistemic violence to more dialogical ways of knowledge production, we face the ethical responsibility of engaging in an ongoing search for appropriate research approaches in each specific context that respect the idiosyncrasy, narratability and unfinalizability of (lived) experience. Such approaches can take many shapes and sizes, but all open up dynamic spaces in which knowledge is continuously produced and rethought in the intersections and tensions between multiple voices and perspectives. In our quest for such spaces, it might prove worthwhile to explore methodologies that go off the beaten track of traditional academic approaches.

Acknowledgments

We would like to thank Prof. dr. Stijn Vandevelde and Prof. dr. Stijn Vanheule for their support and valuable feedback during the writing process of this paper.

Funding

This study was financed by the Special Research Fund of Ghent University (Grant 01D33515).

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